DOCUMENT RESUME

ED 417 499 EC 306 240

AUTHOR	Barlow, Thomas
TITLE	Managed Care for Children with Disabilities and the Interface of Legislative Policies. PREL Briefing Paper.
INSTITUTION	Pacific Resources for Education and Learning, Honolulu, HI.
SPONS AGENCY	Office of Educational Research and Improvement (ED), Washington, DC.
PUB DATE	1997-10-00
NOTE	10p.
AVAILABLE FROM	Pacific Resources for Education and Learning, 828 Fort Street Mall, Suite 500, Honolulu, HI 96813-4321; telephone: 808-533-6000; fax: 808-533-7599; e-mail: askprel@prel.hawaii.edu; World Wide Web: http://www.prel.hawaii.edu
PUB TYPE	Information Analyses (070) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Child Advocacy; Chronic Illness; *Disabilities; Family Needs; Federal Legislation; Financial Support; Government Role; Health Insurance; *Health Maintenance Organizations; *Health Needs; Health Services; *Needs Assessment; Special Health Problems; *Trend Analysis
IDENTIFIERS	*Medicaid

ABSTRACT

This paper addresses issues related to health care reform and the impact of managed care on health care services to children and youth with disabilities or special health care needs. Federal laws governing support for children with disabilities and their families are listed and briefly reviewed, noting a trend toward the dismantling of guarantees for children with disabilities. Major health care needs of disabled and chronically ill children are noted, including the finding that about 10 million children have no health insurance, that massive cuts in Medicaid could cause another 5 million to lose health coverage, and that one-third of children with chronic illness or disability have no source of care. Concerns of families are also listed, such as lack of sufficient family income, inability to locate necessary services, and difficulty in communicating with the health care provider. The current status of Medicaid-managed care for disabled children is summarized and model state programs are noted. Sixteen recommendations for advocates of children with disabilities are offered, such as to become informed about issues of public and private financing of health care, to insist on guaranteed access to medically necessary speciality care, to lobby legislative bodies at all levels, and to form coalitions with others concerned about children and health. (Contains 24 references.) (DB)

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ED 417 499

PREL BRIEFING PAPER

October 1997

PACIFIC RESOURCES FOR EDUCATION AND LEARNING

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Managed Care for Children with Disabilities and the Interface of Legislative Policies

by Thomas Barlow, Ed. D.*

This paper focuses on health care reform and the impact of managed care on health care services to children and youth with special health care needs. In an effort to control rising health care costs, increasing numbers of Americans, including children, youth, and adults with chronic illnesses or disabilities, are or will be receiving their health care services from managed care organizations. Many states are attempting to control health care costs by enrolling Medicaid recipients in managed care programs. Concern has been expressed about whether the complex health care requirements of persons with chronic or disabling conditions will be met in this new and changing health care environment, which is sometimes characterized by an emphasis on cost containment and preventive health services. Many fear referrals would be limited in a gatekeeper system that emphasizes primary rather than specialty care.

However, managed care organizations offer opportunities for service coordination and continuity of care for children with special health needs and for their families. For this to come about, providers in both the public and private sectors must understand these new systems of care as well as the health and psychosocial needs of children and youth with special health care requirements.

In sum, there are many questions, but, as yet, relatively few answers. There is little in the literature on the outcome data necessary to determine whether the needs of people with special health care concerns will, in fact, be met by managed care organizations. This paper will provide an overview of the many issues for challenged children and adolescents in a managed health care setting.

Federal Laws Supporting Children with Disabilities

A broad range of federally supported programs exists to meet specific needs of children and young adults with disabilities. Services include education, early intervention, health services, social services, income maintenance, housing, employment, and advocacy. However, navigating among programs can be complex and distressing. Some programs are not able to serve all, or even most, eligi-

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*Dr. Thomas W. Barlow is Visiting Scholar, Pacific Resources for Education and Learning (PREL).

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ble clients; eligibility criteria may differ from program to program with some clients falling between the cracks; specific, legitimate needs may not be met by any program. The many federal programs for individuals with disabilities are not a comprehensive system.

Within the field of education, federally supported programs for children with disabilities are relatively comprehensive and coordinated: Individuals with Disabilities Education Act (IDEA) spells out the services to be provided by the local school, parental due process protections, and the federal research and leadership programs.

In other fields, services to children with disabilities may not be unified by a single statutory authority. In some instances, programs were created by Congress to address specific, narrowly defined needs; in other instances, programs were created within the context of larger programs, such as eligibility categories for Medicaid based on disability.

Many federal and state programs have grown or shrunk rapidly in recent years due to a major shift to block grants, which permit states to change critical aspects of a program, such as federal definitions of eligibility criteria and basic services.

In 1990, the U.S. Congress passed and President Bush signed into law the primary piece of federal legislation supporting Americans with disabilities, the Americans with Disabilities Act (ADA). Its purpose is to bar discrimination on the basis of disability. The ADA essentially blended elements of two previous federal civil rights laws: the Civil Rights Act of 1964, which protects minorities from discrimination in employment and in public accommodations, and Section 504 of the Rehabilitation Act of 1973, which states that "no qualified handicapped person shall be discriminated against by any entity receiving federal funding" (Public Law 101-336).

A list of the major federal laws that currently govern the majority of support for disabled children and their families follows:

- Americans With Disabilities Act, 1990
- Individuals with Disabilities Education Act
- Medicaid—Social Security Act, Title V
- Public Health Service Act, 1988
- Social Security Act, Title IV—Adoption/Social Services
- Supplemental Security Income—Social Security Act, Title XVI
- National Affordable Housing Act—Housing, 1990
- Job Training Partnership Act—Summer Employment/Youth Training Program, 1983
- Rehabilitation Act—Title I, 1973, 1978
- Developmental Disabilities and Bill of Rights Act, 1975

By 1995, the national mood had changed significantly regarding how much the federal government should be in the caretaker role for many of these safeguards for children. Included in the changed viewpoint was a major re-examination of health care reform, cost containment, and how individual states should be in control of implementing federal programs. With these sweeping changes, a new era has emerged for the United States, an era full of opportunities and also full of pitfalls, in particular the dismantling of guarantees for children with disabilities.

Challenges

The list of challenges facing children in the United States as a result of sweeping Congressional changes in 1995 are too numerous to mention. However, a few of the special challenges faced by disabled and chronically ill children follow:

- About 10 million children have no health insurance and 800,000 children each year lose employer-provided health insurance. (Children's Defense Fund, 1996)
- Massive cuts in Medicaid proposed by congressional leaders could cause another five million to lose health coverage by 2002. (Children's Defense Fund, 1996)
- Children's access to pediatric subspecialists is often problematic in managed care plans. The HMOs surveyed in one study often lacked a full range of specialists in childhood disorders either on staff or on contract. (National Center for Youth With Disabilities, 1996)
- One-fifth of the pediatricians in one survey reported that HMOs and PPOs denied some of their referrals to pediatric subspecialists.
- One-tenth reported denials for specialized inpatient care.
- Contractual barriers to care for disabled children include the "medical necessity exclusion" and the "experimental treatment exclusion" clauses. (Assessing and Developing Primary Care for Children, 1995)
- One-third of all children and youth with chronic illness or disability have no source of care. Some 38 percent say they have health problems that they have never discussed with any physician. (National Center for Youth with Disabilities, September, 1995)
- An estimated three million children have serious emotional disorders. (Children's Defense Fund, 1996)
- One in every 10 students in public schools today receives special education under the Individuals With Disabilities Education Act. (The Future of Children, Spring 1996)
- The total cost of special education is an estimated $32 billion per year. (The Future of Children, Spring 1996)

Maintaining the health of children with disabilities, keeping them out of the hospital and in schools and communities, requires more than basic pediatric care, immunizations, and screenings. As a result, many experts and consumers already question whether the principles of managed care can accommodate the unique and specialized needs of this population. The subjective nature of many

service and treatment decisions, the lack of a single standard of care and treatment, and the necessary involvement of multiple providers from numerous disciplines, including the schools, do not readily lend themselves to a managed care approach.

Typical concerns for families seeking health care for their disabled children include the following:

- Lack of sufficient family income to pay for services;
- Inability to locate necessary services/personnel;
- Insensitivity to family's difficulty in acquiring services, once located;
- Finding that the child was not eligible for the service;
- Finding that a service provider did not think the child needed the service;
- Inadequacy in both quality and quantity of the service;
- Difficulty in communicating with the caregiver;
- Inability of the family to get to the service; and
- Inadequate time to use the service.

Children with multiple disabilities clearly have more unmet needs than those listed. For instance, coordination of services and monitoring of services needed are particularly important for families of such children. In Hawai'i, an improved system of program coordination is required to fill the gaps in services for disabled children between the ages of three and five and between graduation and the onset of adult services. Program continuity and increased funding are improvements that must be addressed.

In the Pacific region, an additional problem is the availability of quality health care to the large populations of immigrant families, minorities, and those who speak English as a second language. Knowledge of services and access to appropriate care are often limited among those unfamiliar with the society or with the complex health care system.

A particular concern for the families of disabled children, as well as children in general, is Congress' dismantling of long-standing guarantees of help for poor, hungry, ill, disabled, abused, and neglected children. These guarantees have been the cornerstones of federal child survival programs, because they ensure that all those eligible under state and federal rule will get the help they need—regardless of the state in which they happen to live, or the parents they chanced to draw, or the economic conditions in their region. In place of these basic guarantees, congressional leaders have created new "block grants" to states. These fixed payments would carry few or no federal standards. States would have almost complete discretion in their use of the block grant funds, and would not be held accountable in any significant way for achieving improved outcomes for children. (Children's Defense Fund, 1996, pp. xxvii)

Medicaid Managed Care for Disabled Children

As of November 1995, fully half of the states were operating, waiting for approvals of, or developing statewide Medicaid managed care programs under special, experimental federal waivers that would allow them to make enrollment mandatory. Medicaid beneficiaries may find that the quality of their health care is maintained or even improved under managed care that includes regular access to a specific primary care provider. But, they also may find a serious deterioration in care. The rapid shift toward Medicaid managed care has raised many troubling questions, including whether or to what extent:

- Networks have enough providers to meet families' needs;
- Capitated plans provide high-quality care;
- Managed care plans provide culturally and linguistically competent care;
- Network providers are given financial incentives to deny care to patients;
- Managed care plans provide the full range of services covered by Medicaid, including comprehensive services to children as required by federal law;
- Some managed care plans make false or coercive statements to persuade families to enroll;
- Medicaid dollars are diverted from patient care to administrative expenses or profits; and
- States obtain adequate information about the services managed care plans provide in exchange for public dollars. (Children's Defense Fund, 1996, p. 21)

These worries were underscored in 1995 by media coverage of managed care programs—in New York and elsewhere across the nation—that erected barriers to essential health care to keep costs down and profits high. Better safeguards clearly are necessary to ensure that Medicaid managed care programs achieve their promise rather than jeopardize the health of low-income children.

As the primary instrument through which most American families obtain health coverage, private, employer-based insurance represents a critical source of health benefits for children. For nearly two decades, however, the number of children covered by private, employer-based insurance plans has been dropping rapidly. This is because employers are dropping all coverage, ending dependent coverage, or increasing employees' share of premiums for dependents; it is *not* because fewer parents are employed. An average of one percent of all U.S. children, some 750,000, have been losing such insurance each year since 1987. If this trend continues, less than half of the nation's children will be covered by employer-based insurance by the year 2000.

In the late 1980s and early 1990s, Medicaid expansions aimed at children in low-income working families offset some, but not all, of these private insurance losses. Medicaid now covers one in four American children, one in three newborns, and nearly one in two African American children. Medicaid expansions were not enough to offset all of the loss of private, employer-based insurance, much less cover all uninsured children. As a result, today more than 10 million children, or 14.2 percent of all children younger than 18, are uninsured, including 2.8 million children younger than 6.

The one bright spot is the continued phase-in of mandated Medicaid coverage for poor children through age 18, so that by October 1, 2001, all poor children in America will be guaranteed health coverage if Congress does not block-grant Medicaid or otherwise weaken the law. (Children's Defense Fund, 1996, p. 19)

Clearly, there are many challenges facing American children with disabilities and chronic illness. As federal support for children and their families takes on new roles, and as states assume more responsibility in defining and implementing previous federal programs, there are numerous opportunities for success and failure. Following the lead of private health care industry, public health care has also invested in managed care philosophy as a means to contain costs. If costs can be contained, while maintaining high access and quality, then the measure of success of these recent changes is in the balance of cost, access, and quality. The changes are too recent, and the outcome data are too rare as of yet to know how America's children are faring. However, there is great need for vigilance and increased advocacy at all levels to ensure that the gains of previous decades are not lost.

Model State Programs

In a review of the literature, it is clear that there are many model demonstration projects underway in many states, both in private and public health care. Support for disabled children and their families seeking appropriate and adequate health care is alive and well. Most evidence of this good will is within model demonstration projects that exist in single or small numbers of counties. Data from these projects are not sufficiently clear to indicate what success can be expected but are sufficient to indicate merit in persevering.

A few of the states that consistently appear in the literature are Washington, Oregon, New Mexico, Arizona, Hawai'i, Ohio, and Iowa. As the efforts of these states are evaluated, versions of their demonstration projects are likely to spread throughout the nation, affecting the health care of disabled children everywhere. It is hoped that those that fail to serve children well are quickly noticed and replaced by more promising practices.

Recommendations

In conclusion, the future of appropriate medical care for children with disabilities is debatable. Since 1994, Congress has changed tremendously how federal laws and budgets are used. In an effort to downsize federal government, Congress has given much more authority to the states. This change has impacted federal guarantees of non-discriminatory health care for children. As individual states assume more oversight, advocates for children's health care will need to be vigilant and informed.

Careful attention to the following concerns and recommendations is in order. Advocates for children, especially for disabled children, need to

- learn about renegotiating contracts; coordination of care; mental health benefits; durable and disposable medical goods; and physical, occupational, and speech therapy;
- be informed about and insist on family-centered care, community-based services, and coordinated care;
- be informed about federal, state, private, and public financing of health care issues;

- insist on guaranteed access to medically necessary specialty care for patients with chronic illness and disabilities;

- articulate the need for restrictions on certain physician incentive plans;

- support and advocate the training of new physician specialists to meet the needs of patients with chronic illness;

- ensure that, at a minimum, every child and pregnant woman has comprehensive health insurance coverage from a private or a public source;

- strengthen the delivery of health care, including prenatal care, immunizations, and other preventive services, particularly among disadvantaged populations and within traditionally underserved neighborhoods and communities;

- support the use of proposed federal tax cuts to provide comprehensive health insurance coverage immediately to every uninsured child in America;

- support the establishment of a new pediatric standard which will demonstrate that health care decisions for disabled children take into account, and are consistent with, the child's healthy growth and development;

- remove barriers to care, such as utilization review and utilization management;

- know their communities, their unique needs, and key policymakers at all levels, both in private and public health care industries, in order to best influence decisions made affecting disabled children;

- insist on the development of a delivery system with multiple components to serve children with complex needs;

- lobby legislative bodies at all levels to make their cause and presence known;

- support the argument that because the unique developmental needs of children offer perspectives on health care decisions that are far different from similar decisions made about adults, a special layer of skill and expertise should be added to health care for all children; and

- form coalitions of all those concerned about children and their health, being mindful to include many managed care organizations who may simply need a bit of education about the special needs of disabled children.

Regardless of how Congress and private industry conclude their reform, society's interest in healthy children, and in the adequate financing of health care, must be maintained. There is ample room for discovery of new means of service delivery, including managed care options. For instance, if managed care is implemented thoughtfully and with adequate resources, it appears to have potential for improving child welfare and mental health service. Having a single entry point into the child welfare and mental health systems would benefit children and families. In addition, managed care's emphases on prevention, early intervention, and service provision in the least restrictive setting could

bring about needed changes in both areas. Well-run managed care systems could encourage the development of strong provider networks and offer children and families easier access to a broad continuum of coordinated services. Managed care also could offer the benefits of outcome-based provider accountability, consumer involvement, and culturally sensitive services, all hallmarks of recent reform effort in child welfare and mental health. In many locations throughout the nation, some of the best features of managed care are finding their way into plans for the care of disabled children. The future of America's children demands ascertaining the features that work best and making them the norm, while discarding those that sacrifice access and quality of service in the name of cost containment and profit.

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